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ABSTRACT

The document cites research to support the viewpoint that community integration is preferable to institutions for the severely and profoundly mentally retarded. Refuted are such arguments against deinstitutionalization as that retarded people should be segregated, that institutions are a more efficient and less expensive way to provide services, and that some people are so retarded they cannot benefit from educational programing. (SBH)

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# THE COMMUNITY IMPERATIVE:

# A REFUTATION OF ALL ARGUMENTS IN SUPPORT OF INSTITUTIONALIZING ANYBODY BECAUSE OF MENTAL RETARDATION

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## THE COMMUNITY IMPERATIVE: A REFUTATION OF ALL ARGUMENTS IN SUPPORT OF INSTITUTIONALIZING ANYBODY BECAUSE OF MENTAL RETARDATION

In the domain of Human Rights:

All people have fundamental moral and constitutional rights.

These rights must not be abrogated *merely* because a person has a mental or physical disability.

Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Service:

All people, as human beings, are inherently valuable.

All people can grow and develop.

All people are entitled to conditions which foster their development.

Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and

In securing optimum developmental opportunities,

All people, regardless of the severity of their disabilities, are entitled to community living.

## A TIME TO TAKE SIDES

Every fundamental social change is accompanied by active, sometimes bitter debate and confrontation. The deinstitutionalization movement fits this mold. Some say deinstitutionalization is moving ahead too quickly. The data, they argue, do not warrant a wholesale abandonment of institutions for the retarded (Balla, 1978; Baumeister, 1978; Begab, 1978; Ellis et al., Memorandum, October 18, 1978, p. 16; Zigler, 1977, p. 52). Another professional research constituency has heralded community residences as morally and empirically preferable to the institutional model (Baker et al., 1977; Biklen, 1979; Blatt, 1973; Dybwad, 1979).

The ENCOR (Nebraska) and the Macomb/Oakland (Michigan) models of community services are two much heralded, notable examples of systems which have received government and community support. Like other efforts to establish community residences, these systems have experienced resistance, too. And in New York State and in the Washington, D.C. metropolitan area, prospective group homes have even been firebombed. But despite the occasional resistance, community residences are being established at a rapid rate.

In every time of profound social change people must take sides. Indecision, the failure to take sides, is tantamount to a political choice. On the institution question, or might we more accurately call it the community integration question, the time has long since come to take a stand.

## THE CONTROVERSY

Pressures and justifications for continued institutionalization of retarded people abound. Despite recognition in most federal agencies that deinstitutionalization is a goal, social programs as frequently as not promote continued institutional services (Comptroller General, GAO, 1977). While the numbers of retarded persons institutionalized in mental retardation facilities have declined, the numbers of retarded people in nursing homes has increased in equal amounts (Conroy, 1977). Specialization of human services has been set forth repeatedly as justification for segregation. Virtually every state's education and developmental disabilities plan includes this reasoning. Institutions are being held out as appropriate placements for severely and profoundly retarded persons. Private and State economic interests make deinstitutionalization fiscally unprofitable, at least as long as there is an absence of conversion plans for the existing institutional facilities (Blatt et al, 1977), something no state has developed. Local zoning ordinances continue to pose threats, albeit less and less effectively, to group living arrangements for retarded people in residentially zoned neighborhoods (City of White Plains v. Ferraioli, 1974). Some experts have seen the future of institutions and institutional abuse as so permanent and unshakeable that they have proposed euthanasia for more severely retarded persons (Heiffetz and Mangel, 1975). This line of reasoning is strikingly like the United States Marine policy of fire bombing Vietnamese villages to save them. And some states have released retarded people from institutions into proprietary homes and onto the streets, without providing any community adjustment services. Such policies seem almost conspiratorial; predictably, in their anger and disillusionment, some local communities have perceived deinstitutionalization as "dumping."

Our own view is that the principal barriers to deinstitutionalization are not technical ones. Federal program incentives can be redirected. Conversion plans can be fashioned. Exclusionary zoning laws can be and are being reshaped in courts and legislatures. And community support services can put an end to the practice of "dumping." But no amount of tinkering with technical planning matters alone can bring about community integration. The real issue, the prerequisite for making any kind of determination about whether or not to support deinstitutionalization, concerns how people view other people and, more specifically, how people classified as retarded are perceived. Policies of forceably segregating groups of labeled people, whether for protection, punishment, or treatment, frequently reflect the possibility that the subject people have been devalued. In our culture, and in many others, institutions have provided the mechanism for large scale devaluation of certain identified groups, including the mentally retarded. As long as retarded people are socially, economically, and politically rejected, the institution will seem acceptable. But, forsake the devalued role and one must abandon a whole host of prejudicial and discriminatory treatments, the institutions among the most obvious of them.

By definition, institutions deny people community living experiences and limit the opportunities of nondisabled people to interact with their disabled peers. This fact exhibits quite clearly that the pivotal issues with respect of deinstitu-

tionalization are moral – the society is richer, community life more rewarding when all people are valued, when people share in each others' lives – and legal – the constitution protects liberty – and not merely ones of differing treatment strategies. Thus, we do not make a case for community integration on the grounds that community living will always be more enriching or humane, in a clinical sense, than institutional settings, but rather on the grounds that integration is morally correct, that integration is basic to the constitutional notion of liberty, and that community programs inherently have far greater *potential* for success than do institutions.

It is probably fair to hypothesize that some people *believe*, simply as an article of faith, that retarded people should be segregated. That is, some people may hold this belief as a morally sound one, just as we hold the opposite view. Further, we can presume that the rationale for such a belief might be to protect the retarded, to protect "society," or both. At least these arguments have been raised historically, particularly during the eugenics era (Ellis, 1911). Today, arguments for institutional care are made largely on other grounds, mainly clinical ones.

Senior researchers, scholars, social planners, and decision makers have raised seven serious complaints against deinstitutionalization. Critics charge:

* that the allied concepts of deinstitutionalization, normalization, and educational mainstreaming are "little more than slogans . . . badly in need of an empirical base;"
* that some people have such profound retardation that they cannot benefit from educational programming at all and certainly not from community placement. They call for "enriched" custodial care in an institutional setting;
* that the community is not prepared to accept the profoundly and severely retarded and probably never will be;
* that there is no evidence that retarded persons develop more in non-institutional settings;
* that there can be good and bad institutions and good and bad community settings. They argue that neither form of service is inherently bad or good;
* that institutions are a more efficient and less expensive way to provide services, particularly to people with severe and profound retardation;
* that current public policy toward deinstitutionalization is part of a historical swinging pendulum. By this line of reasoning, institutions will become fashionable and favored again, after the community thrust has run its course and experienced failure.

Interestingly, when we move beyond the ideological, moral, and legal bases for community integration, that is when we examine the sociological, psychological, and economic research on institutions and community services we find that what we consider to be right is also best. The available research supports community integration.

Observational data on institutions have revealed shocking evidence of human abuse, in the form of retarded persons forced to live in isolation cells, showers, and barren dayrooms, people washed down with hoses like cattle in a slaughter house, people tied to benches and chairs and constrained in straight jackets, toilets without toilet seats and toilet paper, or stall walls, broken plumbing, cockroaches, unclothed people burned by floor detergent and overheated radiators, people intentionally burned by their supervisors' cigarettes, rooms crowded wall to wall with a sea of beds, children locked in so-called "therapeutic" cages, people forced to eat their meals at breakneck speeds, food provided in unappetizing form (often as mush), and people drugged into quiescence. Observational data repeatedly reveal these and a range of other equally abusive phenomena (Biklen, 1973; Blatt and Kaplan, 1966; Blatt, 1970, 1973; Blatt, McNally, and Ozolins, 1978; DeGrandpre, 1974; Giles, 1971; Holland, 1971; N.Y.A.R.C. et al. v. Rockefeller, 1972; Wooden, 1974; Halderman v. Pennhurst, 1977; and Wyatt v. Hardin, 1971 Taylor, 1977; and Wiseman, 1969). The recent parade of court cases involving issues of institutional life provides another unequivocal source of data devastating to institutional legitimacy (N.Y.A.R.C. et al. v. Rockefeller, 1972; Wyatt v. Hardin, 1971; Halderman v. Pennhurst, 1977).

Even the most modern institutions have fostered routinization and other forms of institutionalization of residents' lives (Blatt, McNally, and Ozolins, 1978). In fact, routinization, degradation, and human devaluation, though not always of a violent, cruel, or unusual nature, seem to be endemic to institutional environments (Goffman, 1961; Vail, 1966; Dybwad, 1970).

One argument frequently proposed in defense of institutions is that abuses result from insensitive and ill-trained or ineffectual staff. This hypothesis is overwhelmingly refuted by the breadth of data

available on the institutional context as a determinant of staff behavior (Zimbardo, 1973; Goffman, 1961; Taylor, 1977).

Another belief frequently used to buttress the besieged institutions holds that underfinancing creates the circumstances for abusive institutional conditions. Yet, institutions have proven to be the most expensive form of "service" for retarded persons. As the Pennhurst, Plymouth and Willowbrook experiences attest, even those institutions where states are expending between $35,000 and $45,000 per resident annually and which have some of the most favorable staffing ratios do not adequately protect their residents from physical and psychological harm or provide even minimally adequate habilitation to clients (Gilhool, 1978; Ferleger, 1979, MARC et al v. Donald C. Smith, M.D. et al). Higher ratios of professional staff and centralized professional services do not seem to improve the quality of services either (McCormick, Zigler, and Balla, 1975).

What else do we know about institutions? We know that interaction between institutionalized clients and other people, either other clients or treatment staff, drops substantially in the institutional environment (Goffman, 1961; Provence and Lipton, 1962; and Giles, 1971). We know that institutions are more often than not unstimulating environments (Flint, 1966). We know that institutionalized residents are not likely to be cared for by a few "primary" caretakers, but by hundreds of different staff over a two or three year period (Hobbs, 1975). We know that institutionalized children frequently become apathetic and isolated (Hobbs, 1975) or overly anxious to gain recognition and attention (Yarrow, 1962). Within just a few hours of entering an institution, residents tend to become dramatically less normal, both in appearance and in interaction with others (Holland, 1971). We know that institutional life can promote perseveration behavior. We know that the people who seem to benefit most from institutions are those who came from what clinicians have regarded as the worst home situations (Zigler and Balla, 1976). In other words, the institution was a relatively positive experience only in relation to more miserable pre-institutional experiences. And we know that people who have been institutionalized for long periods of time become more imitative and more conforming (Zigler and Balla, 1977). We know too that institutions can help infants learn to be non-ambulatory (DeGrandpre, 1974). Ironically, some critics of total deinstitutionalization have themselves reported an inverse relationship between institutional size and quality of care. Institutions with smaller living units are superior to those with larger ones and most importantly, group home residences of 10 residents or less, in the community, tend to be more resident oriented (Zigler and Balla, 1976; and McCormick, Balla and Zigler, 1975). Furtner, a comparison of severely handicapped children in institutional and small community settings provides substantial evidence of greater skills development among clients in the small community settings (Kushlick, 1976; Tizard, 1969).

While an argument has been made that for severely and profoundly retarded persons the institution is a less expensive mode of service than community residences (Zigler, 1978), data have not been provided to substantiate that claim. In fact, available information indicates that if there is a difference, institutions are a more expensive though less effective mode of service (McCormick, Balla and Zigler, 1975). A study of the cost of services for 362 ex-residents of the Willowbrook Institution found a savings of at least 50% and 68% of the subjects were classified as severely and profoundly retarded (N.Y.S. Department of Mental Hygiene, N.D.). Similarly, Judge Broderick found that it cost $60 per day to keep people in disgraceful conditions at the Pennhurst institution and one third that amount to provide community living arrangements (Halderman v. Pennhurst, 1977). In each of the available studies, it is fair to conclude that there are no "economies of scale" in residential services (Piasecki, et al., 1978; O'Connor and Morris, 1978; Murphy and Datel, 1976; Jones and Jones, 1976 and Mayeda and Wai, 1975). If there are differences to be seen, those can best be described as an inverse economics of scale; smaller is less expensive.

Historically, it has been argued, institutions were developed in 19th century America as a response to the failure of communities to meet the needs of the retarded. This is only partially true. It is true that Dix, Howe, Wilbur, Seguin and others formulated the earliest institutions in response to community failure, but the failure was an absence of programs and services *and not a failure of actual community services.* Shortly thereafter, at the turn of the century, large institutions came into being, and not so much as products of benign motives. The latter institutions and the then emerging institutional model were largely a response to perceived social problems created by urbanization and immigration. Their purpose was to isolate the retarded from society. So there is no objective

truth to the claim that we are witnessing the swing of a pendulum, back to a community service model which once, a century ago, failed us. We have never fully explored the potential of community services.

Another argument frequently used to justify institutions hinges on the claim that some people are so retarded that they cannot benefit from educational programming. This thesis has been used to justify "enriched" custodial care in institutions (Ellis et al, 1978). Yet, only if education is artificially limited to academic training can it be argued, as some have, that not all people will benefit from it. We know that all people can benefit from educational or habilitative programming. This conclusion has been drawn by major proponents of community integration (Blatt and Garfunkel, 1969; Dybwad and Dybwad, 1977; PARC v. Commonwealth of Pennsylvania, 1971), as well as by some who have advocated a continued institutional role (Baumeister, 1978; Zigler, 1978).

Critics and proponents of deinstitutionalization do agree that there are both "good" and "bad" institutions and "good" and "bad" community residences. That is, those on either side of the controversy can point to abusive institutions, relatively "good" institutions, bad community settings and good community settings. But, therein ends the agreement. As proponents of deinstitutionalization, we reject the view that good and bad settings will occur equally as frequently in communities as in institutions so long as state involvement remains relatively constant. We believe that institutions have a propensity to spawn abuse. We further believe that community settings have inherently greater potential to afford humane, individualized, and appropriate treatment.

Further, we believe that even so-called "good" institutions can be good only in a clinical sense. Residents may receive competent, even imaginative, educational/habilitative programming. But, the very existence of the institution must be viewed as a failure. Here we must refer to the earlier examination of moral and constitutional rights. Institutions, by definition, limit retarded people from interaction with non-disabled people and limit retarded people from community living. That is not to say that we, nor anyone else, can justify "dumping" retarded people into communities. Further, we expect and know that retarded people may have difficulties in adjusting to community life. To this our response should be not to eliminate the problem (by institutionalizing people) but to help people solve those problems.

Data on community programming support the view that whereas abuses in institutions are to be expected, abuses in community programs are more the exception than the rule. First hand accounts, for example, indicate that deinstitutionalized retarded persons generally are happy or happier about their lives in the community (Edgerton and Bercovici, 1977; Bogdan and Taylor, 1976; Gollay et al., 1978). Moreover, when given an option to stay in the community or return to the institution, well over 75% of those placed in foster homes, group homes, and adult homes would stay in the community (Scheerenberger and Felsenthal, 1976). Further, the data on community adjustment, by whatever standards are applied, yield a consistent pattern of moderate though unpredictable success (Baller, Charles, and Miller, 1966; Edgerton and Bercovici, 1976; Cobb, 1972; Bogdan and Taylor, 1976; Kennedy, 1976; Muelberger, 1972; O'Connor, 1976; and Gollay et al., 1978).

The complement to adjustment is acceptance. Is it fair to say that retarded people, particularly the more severely and profoundly retarded, will not be accepted in communities? No. Despite some instances of violence and other forms of resistance, the history of retarded people in the community is a history of acceptance. In fact, the majority of all retarded people, including the most disabled, have always lived in the community, with their own families and have found considerable acceptance (Saenger, 1957). And charges that the retarded are more likely than others to commit criminal acts are entirely without foundation (Biklen and Mlinarcik, 1978). Even the allegations that property values decline when group homes and other home-like living arrangements for the retarded are located in residential neighborhoods has been proven false (Thomas, 1973; N.Y. State Office of Mental Retardation and Developmental Disabilities, 1978). Finally, if some retarded people find resistance and hostility in the communities, the fair response is hardly to punish retarded persons (by institutionalizing them) for others' ignorance.

## CONCLUSION

The data on institutions and community programming do not equivocate. Institutions have little with which to defend themselves. Community integration seems, in every respect, preferable. Indeed, we ask, when is it time to express

one's moral beliefs? When is it time to enforce constitutional rights? And when is there enough data to support a fundamental social change? At what point must we cease to ask "does it work?" and instead ask "how can we help make it work?"

Even if the data were less clear, even if there were no data to support either side of the controversy, institution vs. community integration, we would support the latter. We make the determination on moral and constitutional grounds.

We believe that all people, however severe their disabilities, must be permitted opportunities to live among their non-disabled peers and vice versa. We believe that people who have been classified as retarded should have available to them the patterns and conditions which characterize the mainstream of society. Indeed, we believe that support services should be available to promote the fullest possible integration of people with disabilities into communities.

To allow for continued segregation of retarded persons into institutions and other forms of residential ghettos can only lend credence to the many fears of, and myths and prejudices against people with disabilities. And no amount of scientific language can mask the fact that segregation benefits no one. We find no reasons, either based in data or moral belief, to support the practice of isolating or segregating retarded persons from the mainstream of communities. If people need services, let them receive them in typical communities. Rational scientific inquiry and moral convictions can support no other conclusion.

The issue of institutionalization, like the issues of slavery and apartheid, strikes at the very core, the very essence of our common humanity. Just as the emergence of Jim Crowism, the Ku Klux Klan, and racist theories of black inferiority do not and cannot justify the conclusion that Black Americans were better off under slavery, neither can neighborhood resistance, exclusionary zoning codes, expert claims that some people cannot learn, or even firebombing of prospective homes combined to justify the conclusion that mentally retarded people are better off in institutions. What is at issue here is fundamental human rights and the quality of the lives of human beings. To claim that some people cannot learn, to place those same people in isolated institutions, and then to suppose that the dignity and well being of those people can be protected, let alone enhanced, is to deny history. And to suggest that some people cannot and should not live amongst their fellow human beings is to deny our shared humanness.

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